

The shifting shadow of HIV-related stigma

The health impacts of HIV have lessened with the advent of antiretroviral treatment and other interventions. However, stigma still casts a shadow over people living with HIV, undermining their health and quality of life. How far does this shadow extend? Four decades into the epidemic, researchers from the HSRC and elsewhere grapple with the different forms stigma takes on in various contexts, and how to address it.

By Andrea Teagle

Almost a quarter (23%) of people living with HIV in South Africa, and a third (33%) in Zambia have experienced some kind of HIV stigma, according to a [recent study](#) led by [James Hargreaves](#) of the London School of Hygiene and Tropical Medicine, using data from 2013 to 2018.

Although HIV-related stigma is [less widespread](#) than it once was, it continues to undermine well-being, particularly when it intersects with other kinds of prejudice – for example, relating to gender, sexual preferences or particular health conditions. An article in a 2022 supplement – a [collection of papers](#) on ‘Getting to the Heart of Stigma’ in the *Journal of the International AIDS Society* – found that women in Canada who faced food and housing insecurity experienced greater HIV stigma. Another [study](#), in Kenya, found that people with Kaposi’s sarcoma, an often-visible HIV-associated cancer, experienced stigma associated with HIV, skin disease and cancer simultaneously.

In the editorial of the supplement, the HSRC’s [Allanise Cloete](#) and [Finn Reygan](#) write with co-authors [Lucy Stackpool-Moore](#) and [Carmen Logie](#) that considering context, human rights, intersectionality and agency can help to inform efforts to address stigma. They note that a partnership model between researchers and marginalised groups that facilitates the co-creation of knowledge is [gaining traction](#) in stigma research. ‘A dual focus on stigma’s harms *and* the ways in which people and communities navigate stigma can avoid perpetrating binary or simplistic notions of powerlessness, vulnerability and passivity ...’ they write.


The impact of stigma

Stigma is often cited as a potential barrier to HIV prevention efforts. In the South Africa–Zambia study, which also appeared in the HIV supplement, Hargreaves’s team investigated whether HIV-related stigma impacts the probability of infection in sub-Saharan Africa. The study was part of the [PopART trial](#), which took place in 21 communities in the two countries.

The researchers outline various mechanisms through which stigma might affect the number of new infections. If individuals fear stigmatisation, they might put off accessing HIV testing – an entry point for HIV prevention services. Those who hold stigmatising beliefs about HIV might underestimate their own risk of infection. (Arguably, it is also plausible that that same fear and judgement might lead people to take greater precautions against contracting HIV, rather than fewer.) For some, stigma might be a barrier to remaining on treatment (for example if they do not wish others to see them taking medication), which makes transmission to others more likely.

Despite these plausible pathways, the study did not find an association between incidence and stigma. They conclude that if future research confirms the same finding in other contexts, then the harmful effects of stigma might not extend to increasing the number of new infections. In the editorial, Stackpool-Moore and her co-authors write that efforts to address HIV stigma should be part of a holistic approach to reducing new HIV infections and improving treatment programmes.

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The authors of the South Africa–Zambia study write that the analysis did not extend to measuring the impacts of broader, overlapping prejudices and discrimination experienced by a range of marginalised and vulnerable groups, such as adolescent girls and young women, transgender people and men who have sex with men. In the People Living with HIV Stigma Index 2.0 in Six Districts of South Africa 2020–2021 study, a research team led by the HSRC’s Allanise Cloete explored stigma experiences of people living with HIV. Conducted in partnership with SANAC, people living with HIV, and the LGBTQI and sex worker sectors, the study found that experiences of HIV-related stigma in healthcare settings were low overall, in line with findings from the PopART trial.

However, in the qualitative study ‘Getting to the Heart of Stigma’, funded by the International AIDS Society, experiences of healthcare stigma were more commonly reported among marginalised groups, like LGBTQI individuals and sex workers.

Internalised stigma

Hargreaves and his team emphasise that addressing stigma remains critical for those already living with HIV. Findings from another study using the PopART dataset found, in line with other research, that adherence to treatment is significantly less likely among people with internalised HIV stigma.

In the People Living with HIV Stigma Index 2.0 study, internalised stigma was widespread among the participants, even as experiences of external stigma were low to moderate across the study districts. Half (49.7%) of participants endorsed measures of internalised stigma, which included statements such as ‘It is difficult to tell people that I am HIV positive’ and ‘I feel guilty that I am HIV positive’. Internalised stigma was higher among men, and among young people between 15 and 24 years old. Rates of internalised stigma also ranged substantially across the provinces, peaking in eThekweni at 77%. This was surprising, given how widespread HIV is in KwaZulu-Natal.

The report also found among people with HIV low levels of resilience, measured by reported effects of HIV status on self-confidence, ability to cope with stress, ability to have close relationships, etc.

Disclosure of positive HIV status to family members, where it is appropriate to do so, has been shown to mitigate the harmful effects of stigma for people living with HIV, and to reduce stigma at a societal level. Higher disclosure rates also point to a reduction in external stigma. In the 2020–2021 study, six out of ten participants (62.8%) reported that disclosing their HIV status to people to whom they were close had been a positive experience. However, Cloete emphasises, “HIV disclosure should only be done in an environment that is supportive, and where people feel safe.”

Cloete and her co-authors recommend the implementation of district-specific anti-stigma campaigns, and psychological support interventions specifically targeting young adults living with HIV in South Africa. Psychosocial support interventions should also be considered for vulnerable and key populations to reduce internalised stigma and increase resilience.

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